

Evaluation of diagnosis and treatment of nasopharyngeal carcinoma in Indonesia

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Valorization

Knowledge valorization implies the transfer of scientific knowledge into daily practice. This chapter describes how the science community and health staff in Indonesia might benefit from our scientific findings presented in this dissertation.

Relevance

Indonesian health care is undergoing major changes in the last few years. Since the introduction of the new health care insurance in January 2014, Indonesia is striving for equity in health care. However, Indonesia is facing an imbalance between supply and demand for this health care. Patients diagnosed with nasopharyngeal carcinoma (NPC) in Indonesia encounter many challenges before diagnosis and completion of the treatment. Prior to diagnosis patients are often not aware of the first symptoms of the disease, do not know where to seek medical help or lack the financial means to do so. Upon engaging with primary care many patients are not appropriately referred, as some medical doctors are not aware of the severity of the disease. Once diagnosed patients have to deal with an inefficient and convoluted referral system.

Indonesian cancer care is decentralized and a nation-wide cancer registry does not exist. For that reason, survival rates and incidence rates are often estimates. The first survival rates of NPC patients included in our studies in Yogyakarta in Indonesia revealed lower figures than presented in international literature.

When patients do not finish their treatment it might affect their treatment response. Or in case they start curative treatment when cure is not possible anymore, it may only do harm and valuable places for treatment for those who could be cured are occupied. Better referral, communication and follow-up could prevent this.

We predict that the ongoing research in Yogyakarta will reveal that the waiting time for radiotherapy for any form of cancer is only increasing. Patients diagnosed in October 2016 are planned for treatment by November 2019. Suffice to say that this may well be too late for most patients with advanced NPC. Improvement in the access to health care is required and this access not only entails sufficient available facilities, but also well trained doctors, affordable treatment and community awareness.

This thesis focused on the current problems in the diagnosis and treatment of NPC and has revealed the necessity of a multilevel approach encompassing patient awareness, primary health care education and an expansion of tertiary care facilities in order to facilitate an improvement in treatment results.

Target groups

The results presented in this dissertation focus on NPC. However, this dissertation can function as a blue print for other types of cancer in Indonesia or in fact also for other low and middle-income countries, struggling with comparable problems, in the cancer care system. The findings of this dissertation can be of interest to many institutions and agencies working in the field of cancer. It may be helpful for civil society groups, including non-governmental organizations to provide cancer awareness on a community or professional level. In order to place cancer awareness and improvement of cancer care on the agenda of the policy makers, evidence of the problem is needed to convince key persons to invest time, money and personnel.

Implementations

The output as described in the dissertation is the results of a longstanding collaboration between the NPC research team in Jakarta, Yogyakarta, Surabaya and The Netherlands. Continuation of the projects is guaranteed with the introduction of new stakeholders from different institutes.

Based on the interviews with the patients as described in **chapter 3** it became clear people with NPC-like symptoms often did not want to be referred to the Dr. Sardjito hospital for a variety of reasons. For those who refused referral, a new intervention was implemented. In ongoing research patients are offered to have a biopsy taken in the district hospital in Wonosari, one of the districts of the province Yogyakarta. Preliminary results show that over 30 per cent of the participants who originally refused a biopsy were diagnosed with an advanced stage of NPC. This proves the importance of community-based activities creating more awareness among community and primary health care workers. These patients would most probably not have been diagnosed if biopsies were not offered in a smaller, more accessible hospital.

In addition, a collaboration between Dr. Sardjito hospital, the district hospital in Wonosari (province Yogyakarta) and the district hospital in regency Banyumas (province central Java), will show the effect of the introduction of a trans-oral brush as a novel screening tool. The aim of this collaboration is to start a study to determine whether trans-oral brushing and quantitative Epstein-Barr virus (EBV) PCR is sensitive and specific enough to become a screening test for nasopharyngeal carcinoma in a risk stratified Indonesian population.

The NPC awareness symposium introduced in this dissertation is a great example of an education program that can be implemented in a cost effective way. With limited resources, many health professionals working in the primary health care centers can be reached, by using the train-the-trainer system. Continuation of this program would be of great value. Based on the NPC awareness program, additional education for medical students on NPC was introduced at the Gadjah Mada University in Yogyakarta. This is a preliminary step; we need to strive for additional training nationwide.

In this dissertation we investigated the possible causes for the patient delay. We introduced an NPC awareness program for doctors to decrease doctor's delay and we revealed the possible causes of poor treatment outcome taking the system delay into account. The biggest challenge will be the changes needed on a system delay level. This dissertation shows the need for a massive increase and improvement of radiotherapy resources.

Innovation

Our findings that improvement of cancer care requires interventions on multiple levels, is the innovative conclusion that we have arrived to in this dissertation. This implies that effort should be put in all the different levels within the cancer care system. So that once a patient is diagnosed with an early stage of disease, a delay of 3 years to treatment can be prevented.

The availability of the right level of resources is a major obstacle, and once this obstacle is removed we have to ensure that people with suspected NPC will seek medical help and will be diagnosed in time for early start of curative treatment.

Other possible implementations

On a community-based level we now have more insight into patient behavior so interventions should focus on the biggest obstacles to not seeking medical help. Any form of community-based intervention should take into account the cultural nuances of Indonesian engagement with healthcare and focus on health literacy. Community members should be aware when to seek medical help but also where to seek medical help. As suggested in this dissertation the development of simple infographics can be of great help.

The implementation of a better communication system could have a direct effect on all three levels of delay as defined in this dissertation (patient delay, doctor's delay and system delay). Currently we are developing a mobile application to improve the communication between the communities, patients, doctors and specialists. Difficulties during our studies were the often changing mobile numbers of our patients. This mobile application could avoid loss to follow-up. It could be used as a NPC awareness tool for both patients as well as for (para-)medics working in the primary health care centers and function as a tool to provide information regarding treatment and resources available. In this way, unnecessary traveling can be avoided and reminders can be sent when patients are required to attend the hospital. Also, this mobile application can provide the information required to convince local government to invest in better and more resources for cancer patients.

Findings as described in this dissertation together with our future findings may contribute to recommendations to improve cancer care. Our results strengthen the idea that on all the levels in cancer care e.g. patient delay, doctor's delay and system delay improvement is needed. All of our publications are open access publications to ensure anyone interested in this field can access our information.

